Proposed Work Plan for 16-142

Monthly meetings (2 hour duration) with likely need to develop topic specific subgroups to meet with greater frequency-

Requirements of 16-142: ...submit reports to the council, the Governor, and the committees of cognizance re: the efficacy of support systems for children and young adults (<21) with developmental disabilities with/without co-occurring mental health conditions

Purpose of 16-142—define the problem. Children and youth with complex or untreated developmental disabilities (with or without) mental health disorders are at risk of or experiencing repeated or prolonged hospitalization or other institutional care and may not have access to sustained and effective support for themselves and their families, provided in the least restrictive environment. Such children may and do rely on emergency department or hospital level of care because they have lacked access to appropriate, *sustained* community and home —based programs and now their needs exceed or appear to exceed available services. Unmet treatment and support needs can have potentially devastating effects on the entire family system.

Propose that phase 1 be fact finding and description of what is with analysis of gaps and unmet needs.

Develop focused information request for presentation/reporting to the committee for the relevant agencies (both quantitative and qualitative)

Phase 2 be findings and recommendations for systemic reforms/improvements

How many children in CT have significant developmental challenges? Where can this information be obtained? (Birth to Three, Special Education data, healthcare data for population information... DDS/DCF., where else?)

How do the various child and family-serving systems think about "needs" (both child-specific and family) and how are needs assessed? [Needs may include :basic and disability specific information, basic needs (including housing and financial), care coordination, parent support, parent education and training, home modification, in-home services and supports for ADL assistance, management of physical health and behavioral challenges, access and availability of community services and supports for children and families, respite options, special education] Request agencies to prepare and deliver presentations to committee and have them include their collaboration and quality assurance activities-how do they measure success?; how much are they spending? What do we know about who is not being served?

Report 1: due July 2017

Propose metrics for evaluating the quality of state-funded services that can be utilized by the funding state agencies

Propose any statutory changes needed to promote effective service delivery

Propose any other changes needed

September 2016: Kickoff meeting

- Vision statement –what do we want /what does CT want for all children with significant developmental challenges and their families?
- Statement of the problem-why are we doing this-need to define scope
- Propose developmental approach to fact finding and discussion of needs

October/November 2016: Birth to 5 (scope of need; what do we have for children with complex developmental disabilities and their families, who needs what, who are missing, how well are we doing it)

- Who is currently responsible to do what (public, private) CT AAP/Healthcare, OEC, LEAs, DSS, Private providers, DCF,
- How do children and families currently access and experience services and supports
- How are services funded
- How is care coordinated
- How are needs currently being assessed
- Interagency initiatives
- What are the current quality measures utilized
- What are the current gaps in services
- Challenges

December/January 2016-17: School-age/Pre-Adolescent 6-12 (scope of need; what do we have, who needs what, who are missing, how well are we doing it)

- Who is currently responsible to do what (public, private) Healthcare, LEAs, DSS, Private providers, DCF, DDS, OPA
- How do children and families currently access and experience services and supports
- How are services funded
- How is care coordinated
- How are needs currently being assessed
- Interagency initiatives
- What are the current quality measures utilized
- What are the current gaps in services
- Challenges

February/March 2017: Adolescents 13-17 (scope; what do we have, who needs what, who are missing, how well are we doing it)

- Who is currently responsible to do what (public, private) Healthcare, LEAs, DSS, Private providers, DCF, DDS, OPA
- How do children and families currently access and experience services and supports
- How are services funded
- How is care coordinated
- How are needs currently being assessed
- Interagency initiatives
- What are the current quality measures utilized
- What are the current gaps in services
- Challenges

April/May 2017: Young Adults 18-21 (scope; what do we have, who needs what, who are missing, how well are we doing it) Who is currently responsible to do what (public, private) Healthcare, LEAs, DSS, Private providers, DCF, DDS, DMHAS, DOL, OPA

- How do young adults and families currently access and experience services and supports
- How are services funded
- How is care coordinated
- How are needs currently being assessed
- Interagency initiatives
- What are the current quality measures utilized
- What are the current gaps in services
- Challenges

Develop across agency/transdisciplinary measures of quality of services funded by the state-what quality indicators should/could be used? Access, availability, child/family well-being measures? Dosing and duration issues; care coordination, interagency partnerships-examine other service systems (such as MH) as this work has been developing over the past 10+yrs. Focused treatment and interventions vs. sustaining supports. Suggest adding BHP Beacon leadership as they have significant expertise in this.

Report 2: due January 2018:

Assessment of early intervention services available

Assessment of the system of community-based services

Assessment of the treatment provided by congregate care settings and how quality of care is measured

Assessment of how SDE, LEAs, DCF, DDS and other appropriate agencies can work collaboratively to improve educational, developmental, medical and behavioral health outcomes and decrease risk of entering institutional care

